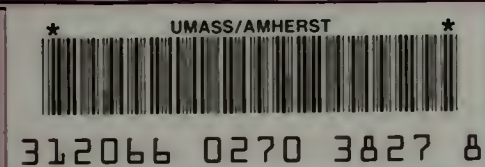


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Governor's Commission on Mental Retardation

Nursing Homes as Residential Placements for Persons with Mental Retardation

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*Report from the Commission's Public Hearing held
Thursday, February 1, 1996 in the State House.*

Nursing Homes as Residential Placements for Persons with Mental Retardation

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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The Commission is especially grateful to Bridget Berry for her assistance in the development of this project.

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Prologue and Dedication

Over the last three decades, the fate of persons with mental retardation living in nursing homes has been a passionate concern for a few untiring advocates for persons with mental retardation. Often eclipsed by other policy and programmatic initiatives, the "nursing home problem" was never forgotten. It is unfinished business. Over a year ago, the Governor's Commission on Mental Retardation received a complaint questioning the appropriateness and quality of care of a nursing home placement for an individual with mental retardation. What subsequently happened is recounted in this report, which describes what we learned, how we learned it, and what options exist for providing more appropriate care.

We dedicate this report to the memory of the individual who alerted the Commission to this issue. Mrs. F. Louise Johnson (1914-1994) was among the most ardent and passionate advocates who ever graced the Commonwealth. Her concern for persons with mental retardation is the stuff of legend. We cannot match Mrs. Johnson's energy, but we can emulate her dogged determination to make things better for all persons with mental retardation.

Introduction

"The money to fund people is available through Medicaid, but the restrictions are so stringent that the people cannot move...because Medicaid will only support the person in [the nursing home] even when there's an appropriate community placement available at the same cost. People's lives are too important to allow this bureaucratic glitch to continue. We must find the mechanism to allow the funding to support the person in whatever kind of setting is appropriate." --Sherri McCann, C-Marc Industries

"The social benefit is clear. Not only are individuals with mental retardation diverted from restrictive nursing home care, but with appropriate supports they can experience increased community membership and access existing services designed for seniors." --Maggie Nygren, Kit Clark Senior Services

"What ever you do, please do it as quickly as possible because there are a lot of people like me that want to be in the community." --Andy Cowling, resident of Falmouth Nursing Home

Concerns about the quality of nursing home placements for persons with mental retardation have persisted for decades. For the past 25 years, the mental retardation services system has been fueled by a commitment to intensive, highly individualized supports. The vision of a life richly led in one's home community contrasts sharply with the perception of nursing homes as bleak, impersonal institutions providing minimal services. Sparked by an individual complaint about the quality of a nursing home placement, the Governor's Commission on Mental Retardation and its staff have embarked on a year-long study of the issue.

The Governor's Commission on Mental Retardation is required to hold at least two public hearings annually. One of the mandated purposes of these hearings is to highlight "the quality of publicly-funded services available to citizens with mental retardation." Accordingly, the fifth public hearing sponsored by the Commission was devoted to examining the issue of nursing home placements and community alternatives for persons with mental retardation.

Both oral and written testimony was solicited from nearly one thousand individuals with mental retardation, their families, providers, advocates, state agency officials, legislators, and others. The hearing was held on Thursday, February 1, 1996 at the State House in Boston. David Braddock, Director of the Institute on Disability and Human Development and Professor of Human Development at the University of Illinois at Chicago, was the keynote speaker. Over one hundred persons attended the hearing. Forty-one individuals testified, and 33 submitted written testimony.

This report highlights the complexities of the nursing home issue in four sections:

- the use of nursing homes as residential placements, including an historical overview and a description of pre-admission assessments;
- the characteristics of persons with mental retardation who live in nursing homes;
- strategies to reduce the use of nursing homes as residential placements for persons with mental retardation based on the testimony from the public hearing;
- the recommendation of the Governor's Commission on Mental Retardation.

The Use of Nursing Homes as Residential Placements for Persons with Mental Retardation

I. Overview

The Impact of Federal Financing In 1965, the Medicaid program expanded to allow states to receive federal reimbursement for skilled nursing facilities (SNFs). With this funding, nursing homes flourished. By 1971, the number of nursing home beds had nearly tripled from 319,224 in 1965 to 944,697 (Mitchell and Braddock, 1990). At the same time, large state institutions for persons with mental retardation were engaged in a dramatic contraction of services, both by restricting admissions and by discharging many residents, often directly to nursing homes. Some state institutions also reclassified parts of their programs as nursing home beds in order to take advantage of the federal reimbursement program (Mitchell and Braddock, 1990). These dual processes-- the expansion of nursing home beds and the reduction in census of the state institutions --resulted in a significant increase in the number of persons with mental retardation living in nursing homes.

In 1967, Medicaid's fiscal support expanded yet again to include intermediate care facilities (ICFs). This increase in funding sustained the viability of nursing homes as residential placements for persons with mental retardation. Robert Gettings has noted that in the late 1960s there was a widespread perception that virtually any placement was better than continued care in a state institution. After 1967, "admission to a nursing home could be rationalized for practically any mentally retarded person..." (Gettings et al., 1988).

The Advent of the ICF-MR With the passage of Public Law 92-223 in 1971, Congress attempted to improve the conditions for persons with mental retardation in nursing homes as well as in state schools. P.L. 92-223 mandated that the same federal financial

participation provided to generic nursing homes must also be available to programs specializing in the care of persons with mental retardation, now designated as Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR). The designation of the state institutions and the later development of community-based ICF/MR's dramatically improved the quality of services for persons with mental retardation. However, few persons living in generic nursing homes benefited from this new funding stream.

Nursing home placements were so frequent that by 1977, 17,000 more people with mental retardation lived in nursing homes than lived in community residences nationwide (Lakin, White, Prouty, Bruininks, & Kimm, 1991).

The Challenge of OBRA'87 States were originally responsible for monitoring their Medicaid supported, long-term care facilities, but the National Nursing Home Survey of 1977 revealed substandard conditions and a mismatch between the services

available and the needs of many nursing home residents. As a result of this survey and renewed concerns about the quality of nursing home placements for persons with mental retardation, the federal government took a more active role in the monitoring process and began to conduct "look behind" surveys in order to assess the conditions and services offered to nursing home residents. Based on its own monitoring and research, the Health Care Financing Administration (HCFA) "expressly stated that nursing homes can be considered appropriate placements for only a small percentage of persons with mental retardation" (Lakin, Hill, & Anderson, 1991). Congress once again attempted to improve the conditions in nursing homes and passed Public Law 100-203, the Omnibus Budget Reconciliation Act (OBRA) of 1987. One purpose of P.L. 100-203 was to eliminate inappropriate nursing home placements for people with mental retardation by restricting Medicaid funding to only those individuals who needed the extensive nursing services offered by such facilities.

Beginning January 1, 1989, all states were required to conduct a Pre-Admission Screening and Annual Resident Review (PASARR) on all nursing home residents with developmental disabilities in order to assess the appropriateness of their placements. With the advent of PASARR, only people whose primary need was for nursing services could be admitted to nursing facilities. Inappropriately placed residents were to be moved by April 1, 1990 to settings better able to meet their needs. Persons who had lived in a facility for more than 30 months prior to the first PASARR were to be given the option of moving or remaining in the nursing home with active treatment (later known as specialized services) provided by the states.

Each state was now required to develop criteria to determine the appropriateness of placements, to design its own PASARR, and to provide alternative housing options for people who would be moving out of nursing homes as a result of the screenings. If states could not meet the deadlines for the design and implementation of the surveys and the relocation of people who were inappropriately placed in nursing homes, they could submit an Alternate Disposition Plan (ADP) and request an extension for implementation of the law until October 1994. Forty-five states, including Massachusetts, received extensions that averaged 38 months (Mitchell and Braddock, 1990).

II. The Massachusetts System of Pre-Admission Screening

A. Medicaid Pre-Admission Screening

All individuals whose admission to a nursing home will be paid for by Medicaid are evaluated to determine if they require nursing home care; this evaluation is called a **Need for Nursing Facility Assessment**. While the local Executive Office of Elder Affairs (EOEA) is considered the "responsible party" for this process, most assessments are completed by delegated hospitals and certified home care agencies. Delegated hospitals make the determination of whether or not someone should be discharged to a nursing home. Generally, the local EOEA office cannot overrule their decision. Home care agencies complete the assessment while the local EOEA determines the appropriateness of the nursing home placement.

Although Massachusetts regulations state that nursing home fees will not be covered unless "all other community options and alternatives are determined inappropriate or unavailable," the eligibility requirements of nursing home admission are actually quite flexible. Persons seeking admission to a nursing home paid for by Medicaid must have the following needs:

- *one skilled nursing service or therapy daily* (this includes a daily insulin shot, change of sterile dressings, tube feedings, physical therapy after a stroke etc.),
or
- *nursing supervision of unskilled services that are necessary to promote the recipient's recovery and safety* (i.e. needs 24-hour supervision),
or
- if the person needs skilled nursing or therapy services only *three times per week*, he or she may be eligible if there is a need for help with *at least two ADL skills* (bathing, dressing, toileting, ambulation, eating).

Because nearly every person with mental retardation who needs long-term care requires assistance with ADL skills and supervision to promote safety, *virtually all are eligible for nursing home admission*.

The staff of the Governor's Commission met with five nurses responsible for the oversight of the Need for Nursing Facility Assessments. Each nurse works for a local elder affairs office and processes hundreds of applications per year. Because so many of the cases are assessed by a delegated hospital or home care agency, these nurses actually evaluate only a few cases each year. Thus, each nurse has seen only a very small sample of persons with mental retardation who are seeking nursing home admission. They noted that within this small sample, persons with mental retardation have similar medical needs to the general nursing home population but tend to be younger. Only one interviewee has ever declined admission to a person with mental retardation. When asked what was the most common situation in which nursing home admission was sought for a person with mental retardation, all responded that a significant illness of the principal caretaker was the primary precipitant. All had

screened people who were living in DMR-funded residential programs, and they felt nursing home admissions were appropriate. One interviewee stated that "they [group homes] hold them too long."

The nurses were asked what would prevent unnecessary nursing home placement for all segments of society. They responded that while adequate community programs exist, **funds are inadequate** to maximize placement. They also said that **aggressive discharge planning** back to the community is critical. All agreed that the acute care hospitals do not have the time to develop adequate discharge plans, so the burden falls increasingly on the nursing homes which have little expertise in this arena. (Only one interviewee felt that nursing homes know how to do discharge planning, and that this is a recent skill brought about by the increase in short-term admissions to nursing homes.) Several interviewees noted that an **increase in family supports** would also help. Because families are generally overwhelmed at the time of nursing home admission, they are not willing to pursue community-based care. If adequate care were available earlier, families might be less likely to favor nursing home admission.

Medicaid Financing of Nursing Homes in Massachusetts

- Medicaid paid for an estimated \$1.5 billion in nursing home services in FY'94.
- 73% of all nursing home residents are funded through Medicaid.
- The Median Daily Total Revenue for nursing homes increased by 30% between 1989 and 1993.
- Between 1989 and 1993, the number of nursing home beds increased by 5% from 47,813 to 50,205. Utilization has remained stable at 95%.
- The 1993 Median Daily Revenue was \$115.15.
- 80% of all nursing homes operate on a for-profit basis.

Source: Massachusetts Rate Setting Commission, 1995

B. Pre-Admission Screening and Annual Resident Review

In order to comply with OBRA '87 regulations, the Department of Mental Retardation contracted with MetroWest Developmental Disabilities Services to implement its Pre-Admission Screening and Annual Resident Review (PASARR). The assessment tool was designed by Seaside Educational Associates in 1989, and each year revisions to the tool are made by MetroWest.

If a person is found to be eligible for a nursing home and appears to have mental retardation, he or she is referred for a PASARR. If the PASARR evaluation determines that the person has mental retardation or a related condition, and he or she is later admitted to a nursing home, PASARR will conduct an annual screening. During both the pre-admission screening and annual reviews, MetroWest conducts an assessment of the individual's needs and determines the following:

- Does the person need specialized services (such as day programming, recreation, counseling)?
- Can those needs be met in a nursing facility?
- Do those needs exceed that which can be provided by the nursing facility, with or without specialized services?
- Is there an alternative residential setting that would more appropriately meet the person's needs?

During FY'96, 2146 PASARR screenings were completed, including a total of 384 pre-admission screenings.

III. The Persistent Stability of the Nursing Home Population

Over the past twenty years, mental retardation services in Massachusetts have undergone an unprecedented intensity of reform. Through an infusion of federal and state funding, the DMR budget has grown from \$105 million in 1977 to \$818 million in 1992 (Braddock et al., 1995). Many people have left state run institutions for smaller, community-based placements. Day services, transportation, family supports and respite have all been expanded. Unfortunately, persons with mental retardation living in nursing homes have been largely unaffected by these changes. The number of nursing home placements for persons with mental retardation has remained stable, and in contrast with DMR services, nursing homes have become more institutional rather than less. Dr. David Braddock noted during the public hearing that *"nursing homes appear to have changed very little in the past decade in response to the important questions being raised in professional and policy areas about appropriate standards and programmatic goals for residential services for persons with mental retardation."* Currently, Massachusetts ranks ninth in the nation in its nursing home usage by persons with mental retardation, highest among the New England states.

Table 1

Massachusetts: The Use of Nursing Homes by Persons with Mental Retardation

Year	1977	1986	1996
# of nursing home residents with MR	1700	1360	1746
% of all residential placements for persons with MR	19%	15%	17%

(Sources: Institute on Disability and Human Development, University of Illinois at Chicago, Braddock et al., The State of the States in Developmental Disabilities, 1995)

The reasons that nursing homes are used so consistently by persons with mental retardation are clear. Although mental retardation services received a significant increase in funding, new monies were generally devoted to improving the quality of existing services rather than on rapidly expanding the number of residential placements. For example, the total DMR budget (including capital expenditures) more than doubled between 1986 and 1992, expanding from \$410 million to \$818 million. During this time period, total DMR-funded residential placements increased by less than 10%, from 7830 to 8595. Nursing home placements for persons with mental retardation grew by 17.5%, from 1360 to 1600 (Braddock & Hemp, 1995). Demand for services has always exceeded availability: waiting lists grow annually. In contrast, nursing homes currently have a 5% vacancy rate - enough empty beds to serve the entire DMR waiting list for residential services. Persons currently living in nursing homes are considered to be underserved rather than unserved by DMR, and

understandably persons who have lost or are about to lose their primary caregiver are given priority over those who remain in nursing homes. In addition, although federal law requires that persons with mental retardation who live in nursing homes have access to community placements and specialized services, these mandates have been largely unfunded. FY'91 was the only year that state funds were targeted to serving persons with mental retardation living in nursing homes, and that \$3 million allocation went to consent decree class members who lived in nursing homes.

Massachusetts is not alone in its persistent reliance on nursing home placements. Dr. Braddock noted in his testimony that in 1977, nursing homes across the nation accounted for 15% of all residential placements for persons with mental retardation. By 1992, they accounted for 12% of all placements. (In fact, in 1992, there are only 2326 fewer nursing home placements than there were in 1977.) Because this population is

aging, more of these placements may now be appropriate. However, as Dr. Braddock noted, *"research studies indicate that between 75 and 90% of mentally retarded residents in nursing homes were appropriate candidates for alternative placements in community settings."*

In 1993, five states (AL, AK, GA, NE, VA) reported that over 25% of their residential placements for persons with mental retardation and related conditions were in nursing homes. Five states (AZ, DE, ID, KS, RI) report that no persons with mental retardation live in nursing homes (Mangan et al., 1994).

An intensification in health care needs is often viewed as the most appropriate reason for nursing home placement, and several testifiers at the public hearing suggested that nursing homes must be included in the continuum of care. *"Although I concur that an individual, abled or disabled, deserves the care of a home and of a caretaker for as long as humanly possible, we must not prohibit the option of nursing home care,"* notes Paul Hudson, President of the Kennedy-Donovan Center, *"the issue...needs to be embedded in the principle of 'quality of care'. If this is always upheld...the choice of a nursing home when appropriate is a viable one."* Yet the recognition of an appropriate role for nursing homes is contrasted by the often impassioned testimony of some providers who are committed to supporting persons with mental retardation throughout their lives. *"Caroline is now approaching a lot of involvement with Alzheimer's disease, we've gotten a core of people around her, including a friend who [is] a lawyer, in-home nursing supports, and our commitment to her...is that she will stay in her home forever,"* asserts Michaela Martin of the Nemasket Group. Chuck Howard, Executive Director of the Cooperative for Human Services, expressed concern about the costs of supporting persons with intensifying needs due to Alzheimer's disease. He suggested that providers were *"gambling"* with their financial well-being *"because as managers, we lack the commitment or the business sense, or something to say that [people with Alzheimer's disease] belong in a nursing home."*

Many testifiers expressed concern that if the medical needs of the persons they supported intensified, nursing home placement would be the only option. Julie Luskin-Purtz, the Director of Health Services for the North Shore Arc, spoke of her concerns about Peter, a 54-year-old man with mild mental retardation and a significant seizure disorder. Peter grew up at Monson Developmental Center, transferred to the community, living at first in a staffed apartment and then gaining more independence. *"What has happened to Peter is the same thing that's happened repeatedly as individuals are aging. His health has begun to deteriorate....His seizure disorder has become more difficult to manage. He has recently lost both of his parents....As we speak, Peter is...sitting in a rehab setting, and he is in imminent danger of falling into a nursing home."* Elizabeth DeBrine, the Director of the Community Membership Project at the Shriver Center, described the fear of her friend, Barbara Wasgatt. Barbara lived in a state school for 41 years; she now lives independently in her own apartment with personal care assistance. She is a national speaker on aging and disability. *"Although she has a strong circle around her, Barbara feels that she is only three steps away from living in a nursing home."*

It is clear that substantive legislative reform and dramatic increases in funding for persons with mental retardation have resulted in little change in the use of nursing homes as residential placements for persons with mental retardation. Most Massachusetts residents who have mental retardation and need long term supports are nursing home eligible, and unlike DMR services, there are over 2000 open beds in nursing homes today. Although both the Medicaid system of pre-admission screening and the PASARR are designed to reduce the number of inappropriate nursing home admissions, it is evident that nursing homes continue to be used for persons with mental retardation regardless of their health care needs.

Testimony from the Hearing:

Several advocates, family members, and former nursing home residents spoke of their experiences with nursing homes.

"I used to be in a nursing home, but they closed it up now and I'm in a rest home. I had no freedom and no choice. I couldn't get a meal of my choice. I couldn't go shopping with my friends. People with problems from the other wing can attack me physically. I tell the staff about it, but they wouldn't do anything....They got away with murder. They shut off the TV at 8:00, and we had to go to bed at 8:00....But they closed it a couple of months ago, and they put me in a rest home now. I get a chance to go out with my friends....I'm much better now."
--Evelyn La Rock, Consumer

"I am here today to talk about people in nursing homes. I don't think this is a good idea because I do not want to share a room with someone...I would not like this because I would lose my freedom and independence. I would not be able to cook my meals or do my laundry. I also would not be able to take walks or be a part of my community. This is why I think that this idea [putting people with MR in nursing homes] is not okay." --Ramona Wilson, Consumer

"Julius Marten was in a state hospital for quite a long time of his life. Then in '72 he was moved to a nursing home and then again to another nursing home. I have to say that where he lives now from personal experience, he is being well-treated and all of his care, he has been well taken care of. He has his own room. But at the same time, he is just a number in a big nursing home. What he strives for is the attention of a small group home, and that's what he would like to get to." --Robert DeMatte, Friend

"My son David is 33 years old, non-verbal, legally blind, mentally retarded. [He] was going to a nursing home after being released from the hospital with pneumonia. He was brought there...because they were supposed to be better equipped to help him recover and to get better care. Very sadly and to my surprise, this was not the case. First...he was sleeping in a hallway all night because he needed the constant supervision of nurses...next he was moved inappropriately to share a room with a very sick man...later I found documents stating that my son had been exposed to hepatitis....After all this, he was transferred to another ward....There David was almost always tied to a chair, restrained around the waist, and slept that way in a hallway again at night....DMR could not find a place for him that was appropriate for his condition....I would thank God for helping get David the right place....He is now in a good home with 7 more peers where he seems happy....I don't approve that any mentally retarded person, unless they are real sick as to require continual care, should be in a nursing home." --Ana Anaya, Parent

Characteristics of Persons with Mental Retardation Who Live in Nursing Homes

I. Literature Review

The literature presents significant evidence that nursing home residents who have mental retardation differ considerably from other nursing home residents. Surveys conducted in 1977 and 1985 revealed that while characteristics of residents with mental retardation who lived in nursing homes were consistent, persons with mental retardation differed from the general nursing home population (Lakin, Hill, & Anderson, 1991). In their 1985 surveys, Lakin et al. noted that people with mental retardation who were living in nursing homes were younger than the general nursing home population: 68% of those with mental retardation were under age 65, while only 12% of the total population were under 65. They received significantly fewer services than the general nursing home population, including physical, occupational, recreational, and speech therapies. Nursing home residents with mental retardation were also healthier than the general nursing home population; they had far fewer heart problems, visual, mobility, and hearing impairments than the total population, as well as a lower incidence of mental illness. Surprisingly, they needed less help with basic activities of daily living skills, such as bathing, dressing, eating, and toileting.

Seltzer, Finaly, & Howell (1988) studied the match between the functional capabilities of people with mental retardation and the environmental opportunities, supports, and services that they received. The researchers proposed a "goodness of fit" hypothesis, suggesting that a good fit between competencies and available opportunities indicated a high quality of life. Thus, persons living in more restrictive settings, such as nursing homes, should have lower functional capabilities than people in more integrated community residences. This hypothesis was not supported by the data. In comparing the health status, behavioral challenges, and availability of formal and informal supports between the two groups, Seltzer et al. reported that "on most of the functional measures, persons living in nursing homes were at least as competent as those who lived in community-based programs." Indeed, they found that persons who were living in the community had significantly more medical problems and behavioral challenges than people living in nursing homes. Persons living in nursing homes were also more isolated from informal community supports including family and friends. This research supports the position that people with mental retardation living in nursing homes are not, on the whole, more cognitively, physically, or behaviorally impaired than their peers living in community programs.

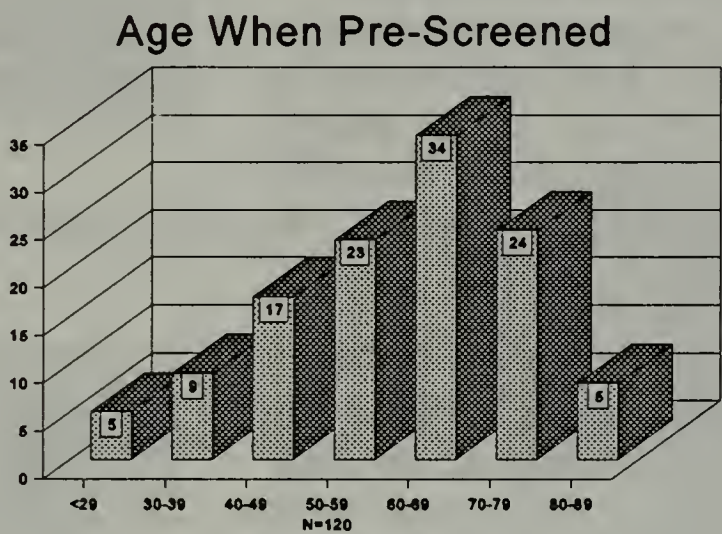
II. PASARR Information

A. Testimony Ellyn Zarek, the program director for PASARR, spoke at the public hearing using data collected from the most recent annual report of the PASARR program. Her testimony confirmed that most persons entering and living in nursing homes would be better served in the community. Summarizing the data for 120 individuals who were pre-screened for nursing home admission between July 1 and December 30, 1995, Ms. Zarek described the characteristics of this group:

Recommended Placement Only one quarter (30) were recommended for nursing home placement by PASARR. Of those 30, 24 (80%) actually went into a nursing home (one died, five remained in the community). Of the three-quarters who were recommended to remain in the community, 60% (54) entered a nursing home. 33 of these were DMR eligible (60%). 21 had not been screened for eligibility.

Age Almost half (45%) of persons with mental retardation who were applying for nursing home placement were under the age of 60.

Table 2



Current Home and Services Most persons with mental retardation enter nursing homes via other institutional placements. 82 (68%) were discharged from acute care hospitals, rehabilitation facilities, rest homes, and private nursing homes. 16 (13%) came from DMR-funded community residences. 17 (14%) came directly from their own or their families' homes.

B. PASARR Annual Report Each year, MetroWest issues an annual report outlining the findings of their PASARR assessments. This information is a resource for developing an understanding of nursing home residents who have mental retardation.

Placement Recommendation Since the inception of the PASARR in 1989, recommendations have been made regarding appropriate placement for each individual assessed. In earlier years, the assessor would specify a particular type of community placement (such as staffed apartment or ICF-MR) which would be most suitable for the person. Since FY'94, the PASARR simply recommends community or nursing home placement. This year, 867 current nursing home residents who have mental retardation were recommended for community placement (MetroWest 1995).

60% of nursing home residents with mental retardation are recommended for community placement.

Age The age of adults with mental retardation seeking nursing home admission ranged between 20 and 95 years old. Among those who are reviewed annually, the age range is 1 to 101. [MetroWest screens children annually; the Medical Review team completes the pre-admission assessment for children.]

In Massachusetts, the average age of a nursing home resident with mental retardation is 58. The average age of the total nursing home population is 83.

DMR Eligibility Most persons with mental retardation who live in nursing homes are not part of the DMR system. Most are not even on waiting lists for DMR services. In fact, among the 1746 adults and children who have mental retardation and live in nursing homes, 917 have never been screened for eligibility for DMR services.

More than half of all persons with mental retardation who live in nursing homes have never been assessed for eligibility for DMR services.

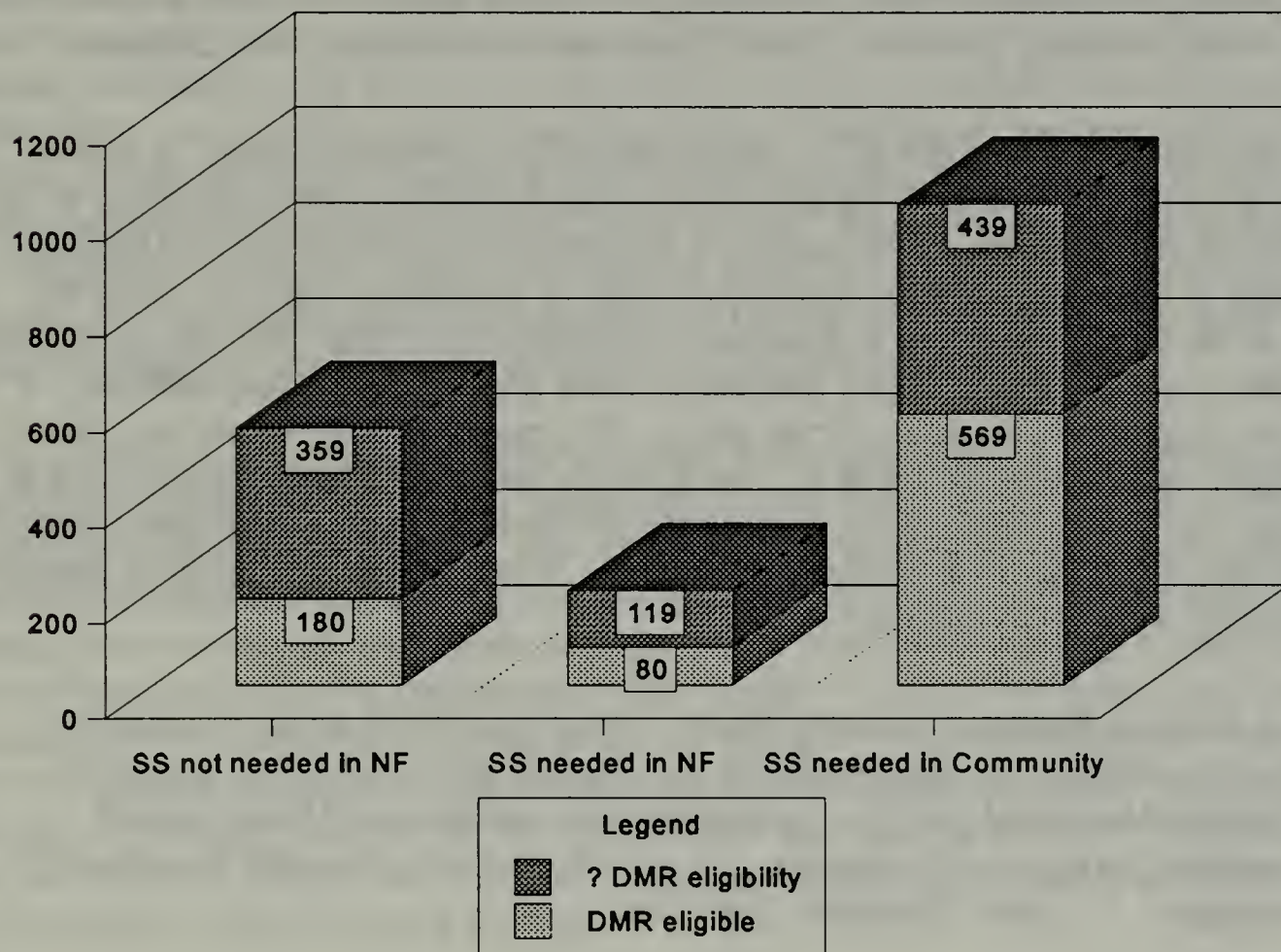
Need for Specialized Services Each PASARR assessment determines whether a person with mental retardation needs specialized services while living at the nursing home. These services include leisure and recreation, physical therapy, communication augmentation, day and vocational programming, independent living, and ADL skills training. Most nursing home residents assessed by PASARR are found to be in need of specialized services, yet they are usually not available.

Over 1000 persons with mental retardation who live in nursing homes are legally eligible for specialized services. Less than half receive them.

Table 3

Specialized Services and DMR Eligibility

	DMR Eligible	Eligibility Not Determined	Total	% of Total
Specialized Services Not Needed/Nursing Home Recommended	180	359	539	30%
Specialized Services Needed/ Nursing Home Recommended	80	119	199	11%
Specialized Services Needed/Community Alternative Recommended	569	439	1008	57%
Total	829	917	1746	100%
% of Totals	47%	53%		



Data Source: PASARR Annual Report FY1994-1995.

It is evident from the PASARR that the characteristics of persons with mental retardation living in nursing homes differ little from those described in the literature. Fewer than one-third of the population surveyed by PASARR are well placed in nursing homes. Nursing home residents with mental retardation are younger than their peers and need so-called "specialized" services such as day programs, recreation, and skills training which would be better met in the community.

Testimony from the Hearing:

A Portrait of Andy Cowling

Several people who attended the public hearing testified on behalf of Andy Cowling. Andy is a man in his mid-40's who was born with cerebral palsy, is legally blind, and has mental retardation. He has been living in a nursing home for approximately 30 years.

"I have visited the individual. I have noticed that he has approximately 50 square feet to call his own. He is in a room in which there are three other beds, so it's not an ideal situation. Andy's lamented the loss of being able to pick friends when he wants. His commentary on being in a nursing home to me is that it's 'too close to death.' He's often been placed on geriatric floors...it's not a place for a man who is still under 45 years old." --Bill Henning, Director, Cape Organization for Rights of the Disabled

"Andy, we had him pretty well set up to maybe try out a community home...It looked really good, a good situation, until he arrived and found that his room was going to be on the second floor. Anyway, to get up to the second floor, as there was no elevator, he would have to transfer to a stair lift at the bottom of the stairs...then he would be transferred at the top of the stairs to a manual wheelchair, and then transferred into his bed. He cannot walk or stand...Now, transfers of this type are very, very difficult....It was [also] very frightening to go up those stairs. It's possible if this community home had an elevator he could have made it. Because for years he's been trying to get to one....Anyway, so this morning when I went into his room he had his television on and what was on there but Barbara Boxer and C-Span. Now that's Andy's level of intellect." --Helen Erickson, Physical Therapist

"Andy's been living in Falmouth Nursing Home. He is one of the senior members. Andy has the capacity for contributing to the community and would have a greatly improved lifestyle if he could get into a group setting -- an assisted living type of situation -- and not be in a nursing home...He used to live at home until they couldn't handle it anymore...." --John Simonds, Guardian

"I just want to say one thing. Whatever you do, please do it as quickly as possible because there are a lot of people like me that want to be in the community. Thank you. If it's good for the handicapped it's good for us." --Andy Cowling, Consumer

III. Testimony from the Public Hearing

The testimony from the public hearing confirms that most nursing home placements do not occur because of intensifying medical needs, but because nursing homes are the only situation available when placement is required. The testimony supports this conclusion and identifies two key sub-populations:

- long-term residents, many of whom were placed in nursing homes from state institutions prior to the consent decree; and
- residents who entered nursing homes because their primary caregiver could no longer support them.

Long-Term Residents Dr. David Braddock noted that during the 1970s, about half of the states in the U.S. used nursing homes as community placements when trying to reduce the census of their institutions. These long-term residents have been excluded from the improvements made over the past twenty years in both institutional and community-based services. Deborah Leonard, a DMR service coordinator, testified on behalf of her caseload, which is entirely made up of these long-term nursing home residents. *"Most of these people have been there for 20 years or more, yet some of them are still in their 40s and 50s....They don't need to live and more importantly they should not be living in nursing homes."* Governor's Commission staff interviewed a 62-year-old woman who receives service coordination from Ms. Leonard. June has mild mental retardation and an affective disorder which is controlled with medication and counseling. June grew up at Dever State School, leaving in her early 20s for a nursing home. When that home closed, she moved to her current placement, another nursing home, where she lives with 35 other persons with mental retardation and chronic mental illness. She has never held a job or even been able to go out into the community on a daily basis. At this stage of her life, she expresses no desire to leave and is pleased to have her own bedroom for the first time in her life.

Loss of Primary Caregiver Several testifiers noted that nursing home admission is often precipitated by the primary caregiver's failing health or death. Lucie Chansky, speaking for ArcMassachusetts, described the situation of a middle-aged man with mental retardation. *"His mother had become ill in her later years, and there was no option for a community residence or apartment. She is in a nursing home, and he is in a rest home because he has nowhere else to live."* One of the most vivid life stories presented at the hearing was that of Jimmy Costa. Jimmy attended the hearing along with his speech therapist and guardian who is also his foster brother. Jim lived with his mother at home for most of his life. He entered the nursing home in 1992 when his mother could no longer care for him due to her deteriorating health. Julia Docking, Jim's speech therapist spoke for him:

"I have come to speak on behalf of James Costa who is a resident of Neville Manor, a nursing home in Cambridge. Although I have only known James for a short time, his determination, his strength, and his desire to live life to its fullest in spite of challenges and setbacks have captured my heart.

Jim was born on August 23, 1943 with severe cerebral palsy, paralysis, and mild mental retardation. He has never walked or been able to care for himself independently.

Jim lived at home and attended day habilitation programs at the Eunice Kennedy Shriver Center until his mother fell ill in 1992. It was determined that Mrs. Costa was no longer able to care for herself and Jimmy in the community, and they were moved to Neville Manor. At the time it was a beautiful arrangement. Jim and his mother were able to stay together and receive the care and support they required. In 1994, Mrs. Costa passed away....Her son Jimmy has never left the nursing home.

...Jim is 52 years old, and he has been living in a nursing home for 4 years. He requires total assistance for his daily activities and living, however does not need the intensive medical services that the nursing home provides. He has no access to community-based service or employment opportunity. He's unable to participate in the social and recreational activities that he craves with others his age and functioning level....As of today the DMR has been unable to secure funding for Jim, and he's been left in the nursing home....Jim is trapped in a place he doesn't belong, lost in red tape and paperwork. I believe his mind was destined for better things."

Through a review of the literature and the PASARR results as well as the testimony from our public hearing, it is evident that most persons with mental retardation are not well placed in nursing homes. The characteristics and support needs of nursing home residents with mental retardation are different from the elder nursing home population. More importantly, people with mental retardation are admitted to nursing homes, not because of significant medical need but, because nursing homes are the only available option when placement is needed.

Testimony from the Hearing:

A Mother's Story

My name is Marianne Laffy. I live in Peabody. And I'm the mother of Peter Laffy....As a result of being struck by a car at age 3, our son, Peter, was brain-injured causing severe mental retardation. He is wheelchair-bound, non-verbal and legally blind. He requires total care, and he is now age 30.

Immediately following his hospitalization he lived at home with us, and at about age 6 he began to stay at Hogan Regional Center as a five-day resident, and he came home on weekends. When his 7 brothers and sisters were all above age 12 in 1981, we decided to care for him at home. And while living at home, Peter attended North Shore 766 program, Monday through Friday. He received physical, occupational, speech and music therapy, adaptive phys. ed. and pre-voc. training. In addition, he had physical and occupational therapy consultation at home. Emphasis was placed on developing skills of independence.

Peter is very socially outgoing and responds well to peers, family, and staff. His mental and physical functioning improved with these therapy services and through participation in community recreation, such as bowling, swimming and horseback riding.

During the winter of 1986-87, Peter developed a hypothermic condition. He was not able to continue attending special ed. classes out of our home. This condition is now controlled. At that time, under medical advice, we decided to find appropriate placement. At that time, in 1987, the state had not yet begun to provide group homes for his level of care. We searched extensively, finally locating the Greenery Extended Care Center in Worcester. For several reasons it is not an inappropriate situation for Peter....The nursing and medical care there has been satisfactory, but unfortunately, because the aides have a number of residents to attend to, Peter's daily independent skills have not been maintained, and he has regressed. Previously through speech and music therapy he was trained to use signs and a buzzer and to make choices with the use of a voice synthesizer. These skills have not been maintained at the nursing home. And because he cannot speak it is essential that he have a means to indicate his needs.

Within the nursing home there is no opportunity for daily structured programming, nor has there been funding available for participation in the community program. Recreation and activity space within the facility is limited to the dining room which has been designated for smoking. Now his usable activity space is limited to the hallway....More recently, all skilled therapies have been terminated. Medicaid will not provide funding.

We have sought to have Peter transferred to an appropriate group home in our area, but there is no space available. Local nursing homes would place him only with frail, elderly and without appropriate activities. Residents in an appropriate group home nearer to his family, with quality care, skilled therapy and daily structures programming are essential to Peter's health and well being. Deprived of these, his mental and physical health will deteriorate. The time and effort previously expended will be thrown to the winds. For the sake of Peter and for all mentally retarded people, we need to assure appropriate residential placement and suitable specialized services." --Marianne Laffy, Parent

Strategies for Reducing the Use of Nursing Homes as Residential Placements for Persons with Mental Retardation: A Review of the Testimony

Throughout the hearing, providers, advocates, family members, and nursing home residents urged the Commonwealth to reduce its reliance on nursing homes as residential placements for persons with mental retardation. Specific recommendations for accomplishing this goal include:

- Re-direct funds from nursing homes to existing community programs.
- Focus on family support.
- Increase collaboration between DMR, other state agencies, and community health care networks.

With the annual costs for nursing home services for persons with mental retardation approaching \$60 million, testimony focused not on expanding funds but on using the current level of funding more efficiently. As John Simonds said, *"I don't think we're asking for more money. I think it's more flexibility of resources where money can be saved, and a much happier, productive situation for the residents."* State officials expressed concern that directing resources away from nursing homes into the community will actually expand the cost of care. They nevertheless voiced commitment to using current resources in more creative ways: *"... [we are] committed to working with all parties to develop creative alternatives for utilizing resources to address it,"* said Ellie Shea-Delaney, Director of Long-Term Care and Rehabilitation Services, DMA (Medicaid). Similarly, Philip Campbell, Commissioner of DMR, reported that *"senior staff from DMR and DMA have initiated discussions to explore ways in which an individual's current funding for a nursing home would be used for alternative community placement."*

Although advocates and officials disagreed over the economics of re-directing funds, there was consensus that the existing community system is capable of serving most persons with mental retardation now living in nursing homes. According to Sherri McCann, Executive Director of C-Marc Industries, *"The provider community is more than able to accommodate the great majority of people who are currently inappropriately placed in nursing homes. We have the staff, flexibility in our programs to meet many diverse and significant needs, and the expertise to design programs that will allow maximum community access.... There is no question that the commitment is there."*

Some Existing Community Support Programs...

The Department of Medical Assistance (DMA) has made a significant investment in nursing home diversion programs. Many of these programs can be used by persons with mental retardation without additional financial or technical assistance from DMR. Other programs, such as the Adult Family Care program, often require additional dollars to meet the needs of persons with mental retardation. Some of these programs are:

Adult Day Health. If a person is nursing-home-eligible, Medicaid will pay for up to five six-hour days per week of this service, which includes transportation, meals, nursing care and recreation.

Adult Family Care. Medicaid will pay for a nursing-home-eligible person to live in the home of a family care provider. This model can be helpful for a person who cannot remain alone overnight. A drawback with this model is its low rate of reimbursement: the family receives a total of \$25 per day, \$15 from the state and \$10 from the person they are supporting (through the SSI check). DMR has supplemented this rate as well as provided additional resources such as respite, counseling, behavioral consultation, and day programming.

Assisted Living. Medicaid pays for some assisted living; others are private-pay and can be quite expensive. Residents usually have their own room and bath. Meals are taken in a common dining area. Lots of assistance with ADLs is available as well as recreation.

Group Adult Foster Care. Medicaid pays a capitated rate to a home health care organization which then provides intensive services to a group of elders who live in proximity to one another (i.e., at an elder services housing complex). 24-hour supervision is not an option but help throughout the day, evening, and weekends is available.

Home Health Aid. Medicaid pays for in-home assistance with personal care.

Personal Care Assistance. Medicaid-funded individual assistance with all aspects of daily living including personal care, housekeeping, transportation. PCA services were originally designed to support people with mobility challenges. They are available to persons with mental retardation especially when used to prevent or delay nursing home admission. Recently, DMA and DMR have signed an inter-agency service agreement permitting the use of PCAs in DMR-funded residential programs in order to prevent nursing home placement.

Maximize Community Supports Throughout the hearing, examples were presented describing innovative ways nursing home placements were prevented, including one in which DMR pays for slots in an Adult Day Health Program (ADH), another in which Medicaid-funded supports supplement DMR residential services, and a third in which a provider functions as a "broker," accessing generic community services and supplementing them with DMR funded individual supports.

Patricia Iyer is the Director of two adult day health programs run by Riverside Community Care. One is Medicaid-funded for 55 elders, the other is funded by DMR for 10 individuals. Ms. Iyer described the benefit of supporting a person with mental retardation through the ADH model: *"It's a wonderful opportunity for elders with mental retardation to socialize with their non-retarded peers, to be part of the community, to be fruitful in pursuing leisure activities, to have health maintenance, and to be able to go back home"*

The Cooperative for Human Services presented information about their efforts to supplement DMR funding with Medicaid dollars and a grant from the John Henry Carter Foundation in order to support nine persons who have mental retardation and Alzheimer's disease. They rely on PCA (Personal Care Assistance), Adult Foster Care, Home Health, and Home Nursing services in order to prevent nursing home admission. An essential component of this program is its pro-active planning by family and professionals in order to anticipate the needs of the person in the final stages of the disease. Many individuals have been able to receive support in their homes throughout their lives. Others, however, are placed in nursing homes either because of family preference or due to the prohibitive costs of in-home support.

Betty Wallace from TILL (Toward Independent Living and Learning), a DMR-funded provider, described a program in which DMR dollars supplement existing community supports to prevent premature nursing home placement. This program, known as Time to Enjoy, supports individuals with mental retardation and their families by arranging for services, activities, and goods necessary for that individual to continue living in the community. In the past two years, 20 individuals and families have benefited; 18 have been able to remain in their homes or in adult family care settings, and two were recently placed in a nursing home. *"This program is about choice, dignity, respect, safety, compassion, and if we want to talk bottom line, it's about saving money,"* says Wallace.

Using community supports to prevent nursing home placement...

Barbara is a woman who is 85 years old and has mental retardation. She lives in public housing. She attends an adult day health program five days a week. She receives support from the VNA and a DMR-funded family support contract. She also receives active service coordination from DMR. These supports cost approximately \$1500 per month, about half the cost of nursing home placement.

Focus on Family Support Keynote testimony from Dr. Braddock emphasized the benefits of cash subsidies to families as a way of reducing nursing home placement: *"Many states have prevented a lot of high-cost placements in nursing homes and in state institutions by supporting families. These are the states that have added or adopted cash subsidy programs. Families are given a great deal of latitude with regard to how they can use these resources, and often a relatively small commitment of resources to a family makes a big difference in whether they decide if a relative needs to be in an out-of-home residential placement."* The contrast between the cost of family supports and a nursing home placement was vividly illustrated by Alvida Martinez when describing the nursing home placement of her brother who has mental retardation: *"We asked for respite care, they wouldn't give it to my mother except for three hours per week...the nursing home was getting \$68,000 per year."*

Maggie Nygren of Kit Clark Senior Services, emphasized the need to support all family members -- not just the person with mental retardation: *"Supportive services for the family can keep the individual in the family unit and out of the nursing home."* Her project supports families who are in crisis, usually when an elderly mother can no longer care for her son or daughter with mental retardation. They help with survivor planning, day programs, nutrition needs, adaptive equipment, in-home supports, and cash assistance. Ms. Nygren presented the case of one family, a mother in her 80s and her son in his 60s who has mental retardation. Mother's health was declining, and she arranged for them to move into a nursing home. Within a month, she decided this was not the life she wanted for herself or her son. She leased an apartment and brought in Kit Clark Services. The mother died suddenly, and the program had to mobilize in order to provide supervision for the son in his own home. Now, eight months later, he attends a day program, uses a homemaker, a home health aide, and a visiting nurse. *"Not only has he learned to use the telephone, he is learning to cook, make friends, and is taking responsibility for many parts of his life....He is successful in the community today."*

Increase Collaboration Testimonies identified two principal avenues for collaboration. The first is to develop partnerships between DMR and local agencies and is exemplified by Project Care Coalition. This group of local agencies, families, and interested citizens, deals with the issues of elderly caregivers and their sons and daughters who have mental retardation. Using the tools of education and advocacy, they are committed to enhancing the quality of life for both the caregivers and their loved ones. Mary Barry, a DMR area director, notes *"Because we have tried to really understand each other's systems, the elder and the DMR, we have been better able to collaborate around each person's life and needs."*

The second avenue for collaboration exists between DMR and the community healthcare providers. Kathy Service, a DMR nurse practitioner with a master's degree in gerontological nursing, described several instances in which a person with significant

needs was supported appropriately through the efforts of a DMR nurse who functioned as a medical case manager and a visiting nurse who provided in-home nursing care: *"Although there are some people who may require intensified actual medical care, or 24-hour nursing services, most individuals' medical needs could be managed with periodic, professional nursing visits and monitoring."*

Another example of this collaborative effort was reported by Peg Ackerman, a nurse practitioner with Community Medical Alliance. This Medicaid funded HMO specializes in treating persons with intensive medical needs (such as HIV) as well as persons with significant physical disabilities. Recently, CMA has enrolled persons who have mental retardation. The mission of CMA is to provide comprehensive home-based care with the goal of minimizing acute care hospital stays and long-term placements. Intensive nurse case management and collaboration with other support systems, often including weekly visits to the patient, is a vital component of CMA's care. As an example, Ackerman described the situation of Dan, a person with mental retardation who receives his medical care from CMA. Dan was hospitalized for treatment of a serious infection and then spent five months in a rehabilitation setting. When Dan returned to his group residence and day program, staff felt overwhelmed by his medical needs. His team contemplated nursing home placement; instead, Dan's guardian enrolled him in CMA. His nurse practitioner visited Dan weekly and formed a partnership with the entire team to manage his medical care. This partnership has been an unqualified success. From July to September, Dan had made 35 visits to an emergency room. Since he has enrolled in CMA, there have been none.

Throughout the hearing there was consensus that funds currently paying for nursing home care must be redirected to increase community-based services. By using existing programs, focusing on direct support of families, and increasing collaboration between DMR and other state agencies, the Commonwealth can improve the quality of life for many persons with mental retardation who are either currently living in nursing homes or are at risk of nursing home placement.

Recommendation Regarding Nursing Home Placements for Persons with Mental Retardation

Concerns about persons with mental retardation living in nursing homes have persisted for decades. To date, legislative reform and dramatic increases in funding for mental retardation services have had only limited impact on this population. The reasons for this are threefold:

- * While Federal reforms have mandated change for persons living in nursing homes, state funding has targeted other populations including those living in state institutions and to a lesser extent those who are turning 22 and the unserved.
- * Because of overlapping mandates, the problem of nursing home placement requires coordinated actions by several state agencies. Currently, the services for persons with mental retardation living in nursing homes are paid for by DMA (Medicaid); the settings themselves, however, are regulated by DPH. Moreover, many nursing home residents are eligible for DMR services, and the Executive Office of Elder Affairs has spearheaded many of the initiatives designed to prevent unnecessary nursing home placement.
- * Data on the persons with mental retardation who live in nursing homes have not been analyzed in such a way that can assist state agencies' efforts to increase community placement.

Specifically, the Governor's Commission on Mental Retardation recommends that an ***Inter-agency Strategic Planning Committee should be established, with the endorsement and support of the Governor's office, to address the use of nursing homes as residential placements for persons with mental retardation.*** This committee should have senior representatives from DMR, DMA, DPH, EOEA and other key stakeholders. Its mission shall be the development and implementation of a strategic plan --with specific time frames and targets for the numbers of persons served-- to accomplish the following three critical components:

- increasing access to specialized services for those persons who are well served in nursing homes but require additional supports.
- developing community-based housing and supports for most persons with mental retardation who currently live in nursing homes.
- maximizing current efforts to prevent unnecessary nursing home placements.

In order to accomplish these goals without a dramatic expansion in the total cost of services, a commitment to redirect current resources away from the nursing homes to the community-based services is essential. Data currently collected through the PASARR assessments need to be analyzed so that comprehensive planning and program development is possible. In particular, studies of the health care needs and multiple disabling conditions among the current nursing home population, as well as living situations prior to nursing home admission, need to be conducted. If unnecessary nursing home placements are to be eliminated, the entire health care community-- including physicians, nurses, therapists, dietitians, and discharge planners-- need to know how to manage medical conditions in the community that once precipitated nursing home admission. In addition, DMR service coordinators and nurses need to know how to access generic community-based resources that assist people to remain in their own homes.

Our hearing revealed pockets of excellence throughout the community services system. We heard examples of collaboration between state agencies and a shift away from narrow service delivery methods to the "brokering" of services with multiple funding sources. All these efforts reveal a capacity and a willingness to address the nursing home issue. This report and its recommendation are fueled by our goal to advance, indeed, to champion, this spirit of innovation.

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